



# GENE NEWS

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## Congratulations

We are lucky to have a community of genetics professionals in our state who enjoy their work and pursue excellence in all that they do. This past summer, five genetic counselors in the state, including two who work in our Department of Health Genetics Program, took their general genetics and genetic counseling board examinations. In December, all five received the good news that they had passed both examinations. They are now officially American Board of Genetic Counseling certified genetic counselors and can use the designation "C.G.C." after their names. Congratulations to Patricia Dock, Lianne Hasegawa-Evans, Kirsty McWalter, Allison Shykowski and Holly Snyder.

Our new geneticist, Julie Ireland (see Coordinator's corner for more information), also took the general and clinical M.D. genetics board examinations last summer and passed both examinations. Dr. Ireland now holds board certification in pediatrics and clinical genetics.

With the newly certified counselors and geneticist, we have a total of 9 board certified genetic counselors, two board certified M.D. perinatal geneticists, two board certified M.D. pediatric geneticists, one board certified Ph. D medical geneticist, and one board eligible genetic counselor in our state providing genetic services as of April 2006.

Another honor that recognizes the work of our Health Department's Genetics Program is the appointment of the Genetics Coordinator, Sylvia Au, to the **Secretary's Advisory Committee on Genetics, Health and Society**. The committee is charged to analyze and deliberate on the broad range of human health and societal issues raised by the development and use, as well as potential misuse, of genetic technologies. The Committee makes recommendations to the Secretary of Health and Human Services, and other entities as appropriate. Some issues that will be addressed include genetic non-discrimination in employment and insurance, reimbursement for genetic services, the use of genetics in pharmacology, and large population genetics studies.

***"The secret of joy in work is  
contained in one word -  
excellence. To know how to do  
something well is to enjoy it."***

*Pearl Buck, The Joy of Children, 1964*



## Coordinator's Corner

I am pleased to welcome two new genetics professionals to our state. We are fortunate to have a new genetic counselor, Elaine Marr, join our Department of Health Genetics Program and help us with our growing list of activities. Elaine received her masters degree from the University of British Columbia Genetic Counseling Program. She is a great addition to our program especially since she is fluent in Chinese and has graphic design experience.

Our other new arrival is Julie Ireland. She is a local girl who completed her medical school training at the Ross University School of Medicine in New Jersey, her pediatrics residency at the University of Hawaii/Kapiolani Medical Center for Women and Children and her genetics fellowship at the Mayo Clinic in Minnesota. We're very happy that she decided to come home to warmer weather. Julie will be joining clinical

geneticist Laurie Seaver at Hawai'i Community Genetics.

Please show your aloha to Elaine and Julie when you have the opportunity to meet them.

## Aloha

Linda Lingle,  
Governor of Hawai'i

Chiyome Leinaala Fukino, M.D.  
Director of Health



**Hawai'i Department  
of Health**  
Children with Special  
Health Needs Branch

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[www.hawaiiogenetics.org](http://www.hawaiiogenetics.org)

Continued on the next page.....

We would also like to bid a fond farewell to Patricia Dock. Patty worked as a genetic counselor at Kapiolani Medical Center for Women and Children for the past five years. She has taken a new position in her home state of Idaho. We wish Patty all the best in her new job



Please contact me if you have further questions or comments

Sylvia Au, MS, CGC  
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## New Series

*This is the first installment of a continuing series of articles describing the various roles of genetics professionals. We hope the information will be useful for healthcare providers referring for genetic services; families who are referred for genetic services, and those considering a career in genetics.*

### GENETIC COUNSELORS



• What is the condition?

#### It's All About Communication

Genetic counselors are health professionals with graduate degrees who are able to answer the types of questions posed above and more. They have special training in genetics, counseling and education and must pass national genetics board exams in order to be certified by the American Board of Genetic Counseling.

Genetic counselors are trained to translate medical information into plain English, which helps them to effectively communicate with families and other health care providers. Their goal is to help families understand the genetic condition and what, if any, are the risks to their children and other relatives. The families are then able to make informed choices about their medical health and options.



• What causes the condition?

• Is the condition inherited?



• Are there risks to my children?



• What treatment and support options do I have if my child or I have a genetic condition?



Genetic counselors work closely with doctors, nurses and other medical specialists to:

- Investigate the genetic conditions in the family;
- Figure out if the condition can be inherited by other family members;
- Explain what is known about the condition;
- Review with families the medical and support options available;
- Thoroughly discuss genetic testing and its implications when medically indicated;
- Advocate for patients and families to help obtain recommended services; and
- Provide information about resources.

Genetic counselors are also educators and resource people. Most genetic counselors have some role in teaching health care professionals, students, policy makers and the general public.

You can find genetic counselors in many areas, including clinical service, education, research, public health, private industry public policy, and administration. The types of jobs open to genetic counselors continue to grow.

In 1988, there was one formally trained genetic counselor in Hawai'i. There are now nine genetic counselors in the state in a number of roles including: prenatal, pediatric, adult, and cancer genetic counseling; public health; research; education; and advocacy.

If you are interested in more information about genetic counselors or training programs, please go to:

National Society of Genetic Counselors  
<http://www.nsgc.org>

# Welcome to the Teacher's Corner



In April 2005, one of our genetic counselors, Kirsty McWalter, had the opportunity to attend the National Science Teachers' Association (NSTA) convention in Dallas, TX. It was a great experience!

Kirsty attended seminars and lectures about genetics education and learned different teaching strategies being used across the nation. She also gave a presentation about the development of the "Teachers' Genetics Resource Kit" that the Genetics Program created for Hawai'i's high schools. Attendees were impressed with the number of free resources collected for the kit! A representative from the National Human Genome Research Institute attended the presentation and, because one of their main objectives is to promote genetics education, she expressed a lot of interest in the kit. Overall, the convention was a wonderful way to network with education professionals and genetics organizations, to discuss the availability of and need for genetics resources, and to share how our program has been involved with educating the community about genetics.

## Genetics Guest Speakers



Please keep in mind that the Hawai'i Genetics Program has genetic counselors and other genetics professionals who would be more than happy to speak to your classes about genetics during the school year. We are able to tailor presentations to most grade levels and are flexible regarding topics. Please contact Kirsty McWalter ([kirsty@hawaiiigenetics.org](mailto:kirsty@hawaiiigenetics.org)) or visit our website ([www.hawaii.gov/health/family-child-health/genetics/newpdf/speakersform.pdf](http://www.hawaii.gov/health/family-child-health/genetics/newpdf/speakersform.pdf)) if you would like to request a guest speaker during your genetics unit!

## Teachers' Genetics Resource Kit – Pilot Study



We have recruited an enthusiastic group of teacher volunteers to pilot our resource kit in their classrooms this school year. The group was given an introduction to the kit in July, and the teachers seemed excited about the rubbermaid containers full of lesson plans and resources – one teacher exclaimed "It's like Christmas!" We have asked the teachers to use the lessons and resources in the kit, and to evaluate their effectiveness. We look forward to getting the results of the pilot study. Once secure funding is in place, we intend to distribute the revised genetics resource kits to teachers throughout the state.

## *The Hawai'i Genetics Program is pleased to announce new federal funding to improve education and follow-up services for Sickle Cell Disease and Trait.*

Sickle cell disease is an inherited blood disorder which can cause anemia and pain. It is more common in African Americans, but can also be found in people of Asian, Caucasian, and Pacific Island background.

With the federal grant, we will expand our Hemoglobinopathy Clinic to provide clinical services for people with sickle cell disease and trait. The Hawai'i Genetics Program is also working with members of the community to develop educational materials geared towards helping families and allied health professionals understand the disease.

We look forward to keeping you posted about this project. More information about the sickle cell disease or grant activities can be obtained by calling 733-9055. To make an appointment at the Hemoglobinopathy Clinic, please call 973-3403.



## Sickle Cell Disease Project

For more information, go to  
[www.hawaiiigenetics.org](http://www.hawaiiigenetics.org)



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**Working Together to  
Accomplish Great Things**

Over the past four years, the Hawai'i Genetics Program has led a multi-state research project to address the financial, ethical, legal and social issues (FELSI) surrounding expanded newborn screening. We also developed educational materials to help address these issues. The final report for the Health Resources and Services Administration federally funded project was completed at the end of August and we are pleased with how much we have accomplished!

Most of the project's findings and products are available on our completely revised  
Expanded Newborn Screening website: **[www.newbornscreening.info](http://www.newbornscreening.info)**

#### **Highlights of the website include:**

- Parent and health care provider fact sheets on disorders commonly included in expanded newborn screening;
- Instructions for parents and providers on how to obtain expanded newborn screening if their state doesn't already do it;
- Details about our research on the financial, ethical and social issues surrounding expanded newborn screening; and
- Suggestions about creating family-friendly educational materials based on our research findings.

Positive feedback about the site continues to come in from parents, providers, and public health programs across the nation. We are proud to have led such an extensive multi-state project and wish to thank the collaborators from Alaska, California, Idaho, Oregon and Washington for their hard work to make this project such a great success. Our program will continue to maintain the website and update the information on a regular basis. Our next step is to find additional funding to translate the fact sheets into other languages to make the fact sheets even more useful for parents and providers.

This project was supported by a grant from the Health Resources and Service Administration, MCH Project #: 1H46 MC 00189-04.